Speaker: Margaret Nosek and Stephanie Silveira
Title: “”

Today’s presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

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Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:
Carolyn Carillon
LoriVonne Lustre

The following initials in the transcription record will identify the speakers:
[09:30 AM] Svea Morane: Good morning everyone, and welcome to this session of the International Disability Rights Affirmation Conference. I am Svea Morane, and go by the name Brian Kaihoi in first life. As a connection with people with disabilities, I am a licensed teacher for students with special needs, including developmental delays and autism. I work at Mayo Clinic, which is the world's largest integrated group practice of medicine, and the largest graduate medical training program in the world. One of my joys is coordinating our work in Second Life, and so I am very happy to be here today.

This session is titled "Is Your Avatar A Bulletproof Vest?" and will be presented by Dr. Margaret Nosek and Stephanie Silveira. Both Margaret and Stephanie are from the state of Texas in the United States. Margaret holds the rank of Professor of Physical Medicine and Rehabilitation at Baylor College of Medicine and Stephanie is almost finished with her doctoral studies in Kinesiology at the University of Houston. Both Margaret and Stephanie have a variety of research interests, projects and collaborations, including work with the Center for Research on Women with Disabilities, known by the acronym CROWD. Research at CROWD has involved women with disabilities and a variety of dicey topics including sexuality, reproductive health, bladder and bowel management, weight management, and self-esteem. As anyone can imagine, these issues are not just physically difficult, but can be emotionally difficult as well.

Margaret and Stephanie are going to talk about feedback women have given them when they discuss some of these topics in Second Life and some of the difficulties and successes they have experienced in trying to make related information available online and in virtual worlds. It is my pleasure to turn the presentation over to Margaret and Stephanie, and let them lead us in answering the question "Is Your Avatar A Bulletproof Vest?". Welcome Margaret and Stephanie.

[09:33 AM] LV (lorivonne.lustre): <transcription begins>

[09:33 AM] Carolyn Carillon: MN: Thank you so much I'd like to thank our previous presenter for an excellent and comprehensive presentation
I was impressed!
I'd like to thank Gentle & to acknowledge Stephanie, our colleague for the last 3 ... 4 years
She's been with us for her whole graduate experience
She's so enthusiastic about working in SL
and transcending the barriers those with disabilities experience
Virtual worlds are an excellent way to break those barriers
I'd also like to acknowledge Thomas
Raise your hand
There he is

I'd like to start talking about our cryptic title
Maybe it'll become clear
We want to talk about how the women in our studies have responding to participating in a virtual world
We'll explore both perspectives -- theirs & ours
The environment & the interventions
I'd like to acknowledge the two studies we've conducted
We're just finishing up now
The second one
is the our study on weight management for women with mobility issues
Our other study in SL had to do with self-esteem
This was more discussion focused
more emotionally centered
We talked more about interaction
self image

Today we're going to talk about the benefits & challenges we've had in SL
The feedback we've received
At the end we'll get your thoughts on how YOU relate to your avatar
How comfortable are you with your avatar
Your perceptions of safety in virtual worlds
Who gave us input?
There were a total of 10 community advisors
All women with physical disabilities
Various types, ages
Different racial backgrounds
A total of 32 women participated
We had 7 sessions
We met once a week
Our advisors worked closely with us throughout
They gave us feedback
We met regularly once a month
They gave us feedback about how to improve the feedback
And we'd share participants feedback with them
The participants filled out forms after each session
They told us what worked & what didn't work
At the end, they had a chance to evaluate each aspect of the program
I'll turn it over to Stephanie now
to talk about the benefits & challenges of doing this work

[09:42 AM] LV (lorivonne.lustre): SS: thank you
It is great to be here and present on what we have learned in SL
Some of the benefits and challenges we have learned

Benefits
transportation and the time burden of attending a f2f program
Very helpful for rural participants or those who are unable to get out
Geographically we could reach a global, not just the US
Anonymity is very important to the participants
Peer support and open conversation

Challenges
Excludes those who had limited computer or internet access
Technological glitches
F2F can be very rich,
F2F is rated highest, but VW like SL rated 2nd
over web conferencing or telephone
Support rated as high
Support from facilitators (M=1.13, 4-pt scale where 1=excellent)
Support from group members (M=1.25)

What did they like best?
Social interaction and support
Comparing SL to face-to-face program:
Somewhat or much more convenient (95%)
People also found it enjoyable
Same (42%) or more (47%) opportunities for social interaction
Same (42%) or more (26%) opportunities for lasting social connections
Participants indicated that they would continue to interact beyond the program

Now over to Peggy
Addressing Physical and Program Access in SL

[09:50 AM] Carolyn Carillon: MN: We took all the feedback we got
and threw it all into a pot
We’d been doing this for 10 years
We’ve had a lot of exposures
We’ve talked to participants a LOT!
We put all these comments into a pot and stirred it
We call this qualitative methodology
We weren’t counting comments but sorting
We want to figure out how do these comments come together
We came up with 6 themes

Theme #1.
How you deal with disability
This sums it up: "It’s difficult to balance whether to replicate disability and accessibility in real life versus allowing fantasy in GoWoman environments."
Here are some of the issues that had to do with replicating disability in SL or not
When you create your avatar, there’s a default image
There's now a wider range but they're all able-bodied
And they're all sexy
(laughs)
Women were saying "I don't look like that!"
"I've never been that skinny"
One of our participants who is lesbian
decided she was going to take a man's body & adapt it
She thought that was kinda cool
She felt she had more accommodations to who she was
But others couldn't find anything
Then others felt liberated
to be able to create a whole new embodiment for themselves
They could adopt a different race
a different body shape
They could let go of their disability
This phrase "to leave your disability behind"
I thought that was provocative
"I've had a disability all my life but here I'm liberated"
In SL, it's hard to find the representations of disability
like wheelchairs
You have to be connected to a place like Virtual Ability
It's a shift in thinking
from USING a wheelchair to WEARING one
If you want to embody yourself, you can't find things like canes
It doesn't work the same in SL
It flops around
It has limitations if you want to replicate your disability
Even wheelchairs look funny if you stand up
Your chair is stuck to your butt
It's inconsistent

Theme #2
“SL poses new kinds of challenges to movement.”
Functional barriers are irrelevant
You have to decide if you want to build in things like ramps
As a political statement
We got into a big discussion about symbols of accessibility and disability
I thought it doesn't matter
Because here it's not necessary
But the advisors were VERY adamant that we needed those symbols
In terms of movement
There are other problems other than running into steps.
You can get trapped in a room or at the bottom of a river not because you don't have physical strength but because you're learning to navigate.
We have to do a lot of training with our participants to teach them how to get out of situations that seem to be hopeless.
Sometimes the computer will glitch and you get logged into run or fly and our participants are lost but we still hear them.
"I can't help myself ... I'm flying uncontrollably"
Or sometimes you have an old computer or bad internet connections.
You're slow to rez.
Your avatar looks like a clown or it can lurch.
That happens to me.
I'll push the navigation controls and I won't move then I'll move a lot.
I can't stop it and I'm smashing into things.
This whole concept of teleporting that's like so Star Trek and I love it but others find it disorienting.
Finally, gestures and animations expressing yourself with a gesture.
In RL, we may have limitations with gestures.
In SL, my avatar is stuck in this position.
I'd love to be able to raise my arms or move around the stage but I'm afraid I'd look stupid.
It's a whole different set of movements.

Theme #3
“Disability affects group dynamics in SL as it does in real life, but differently.”
All our interventions were group-based.
We'd set a time for everyone to log on.
We had to set a time that worked for everybody.
They'd log on and come to our parcel of land.
We'd meet at a specific place meet and talk.
It was real time.
It was fun to watch the dynamics.
We needed ground rules like put your mic on mute when you're not talking.
Tell us when you're done.
So we don't interrupt.
Say your name before you talk
That kind of thing
The women who did not have their disability embodied in their avatar
told us they felt they had to apologize
I feel that way when I introduce myself to someone new
I have this sexy avatar
I tell people that I don’t really look like this (laughs)
Who am I?
Am I the person in the wheelchair?
Or this avatar who’s so beautiful?
It’s a self-examination process
Do you enjoy taking on this new physical persona?
Do you use chat?
Or voice?
For some it’s a choice
For some it’s not
Some have a speech impairment
Typing is easier
We had one person who had a noisy environment who preferred to type
That’s a different way to communicate in a group
Our people valued peer mentoring
But here
The avatar did not give cues that peers had disabilities
or even that they were women
Who’s behind the avatar?
They established that bond of trust
They valued and enjoyed that aspect of the workshops
Some still expressed anxiety at meeting new people
just as they would in RL
They expressed a need for security
The flip side is the fear of being attacked or intimidated
or getting stranded
Some would really get alienated from not being in full control of their avatar
It was disorientating for some
It was difficult to communicate
But for others who had visual impairments in addition to physical limitations
They felt this was an equalizer
Since nobody here had the ability to read a facial expression

Theme #4
“Exercise in SL has effects in real life.”
I want to research this more
This is called the Proteus Effect
where a virtual experience has a corresponding effect on the physical body
When their avatar exercised
they had a higher breathing rate
When their avatar meditated
their body relaxed
One woman told us that if she could feel this good dancing in SL
Imagine how they’d feel in RL
We need to explore this
In medicine it’s the placebo effect
I don’t like that
But what they’re talking about is the power of the imagination
We know all about affecting your body with your mind in negative ways
So why can’t we do this in positive ways, too?
SL gives you the opportunity to practice new behaviours
I preach this but I don’t do it
What if everyday I worked out every day in our SL exercise area
We’ve got kickboxing, weightlifting
What if I started my day by exercising my avatar?
What would happen?
What if I made a routine
of just going to another island
and making one new friend every week?
Just for the fun of it
What would happen?
That would be such a wild new experience
I would NEVER do that in RL
I do have some social groups
but I spend 14 hours a day parked in front of my computer
I’m really focused on my work
The idea of making one new friend each week
That would be fun
SL allows you that opportunity
Even though it’s happening in a virtual world

Theme #5
“There can be a physical disconnect between the virtual body and real-world body.”
This is the opposite of #4
You can create a new identity like I did
A new behavioral identity
In RL you may be shy
Here you can try out new behaviours
If you tend to be stubborn in RL
You can experiment with your relationships here
Do you use your avatar to insulate you?
Does it protect you?
Or does it isolate you?
Is it liberating?
Is it isolating?
There are comments on both sides of that
We did have women who applied to participate
When we trained them
They felt totally weirded out
They said they couldn't relate
They withdrew
But others found it was so cool
They felt so relaxed
They loved the fantasy of it
We're talking about women
Women are very grounded in reality
Because they have to deal with the needs of their family
For some women it's hard to let go of that
But for men
Who are the predominant users of video games
They have an easier time of getting into the fantasy
Some were willing to experiment
Some came back after the interventions were finished
Who said they wanted to explore SL more
But time was a factor

Theme #6
Can communicate what they choose to relating to disability
You can communicate whatever you want to about your disability
Many appreciated the privacy of our island
They didn't have to share anything they didn't want to share
They didn't worry about that awkwardness of the first contact with someone new
You know when some people who speak too loud
Because they assume you can't hear if you're in a wheelchair
Or how some bend down to your eye level
But it's different with avatars
And then there was the ability to talk about difficult topics
"...I felt like we were able to share more freely than we might have done without the avatar or SL."
This environment gave them the privacy and confidence that they could discuss very sensitive topics

So finally I want to open it up
to ask you
How do you regard your avatar?
Is it a bulletproof vest
or a magic carpet
or both?
Do you feel more or less open to discussing dicey topics?
What are your thoughts?
Let's open the floor

[10:16 AM] Fidget (fidgetswidgets): My avatar is magick! I can constantly change it. I can wear my mind or hide my thoughts as I see fit. I LOVE my avatar.
[10:17 AM] Ruby Vandyke: I feel more open to discussing topics. I love my SL and my avatar.
I identify strongly with my avatar to the point I've adopted her name as my RL nickname.
[10:17 AM] LV (lorivonne.lustre): <<me too Ruby>>
[10:17 AM] GraceyLaceyLou: "My avagaw awwof me go be abwe go geg oug of my mind
and abwe go be whag i wang wigh oug now one making me feew afhamed of myfewf!"
[10:18 AM] Ruby Vandyke: yes, I introduce myself as 'Ruby' in RL now, the funny part is -
Ruby gets more phone calls and snail mail than my RL self {laughing}
[10:18 AM] Mook (mook.wheeler) responds to Mook in RL too :)".
[10:19 AM] Gloriejoy (joycie.string): I am who I am in both worlds...the only difference is
that my avatar does not have asthma!! Yay!!
[10:19 AM] iSkye Silverweb: I'm known as iSkye in both worlds, nicknamed "Skye"
[10:20 AM] Eme Capalini: I answer to my SL name in RL.

[10:17 AM] Leandra Kohnke: We actually published on this. We called the human avatar
pair a Havatar.
[10:17 AM] Svea Morane: Just as a reinforcement of your feedback... in our clinical trials,
specifically in cardiac rehab, we have gotten the same feedback from our patients.
[10:18 AM] Mook (mook.wheeler): COMMENT: I would like to send Dhira and Sobra several
academic presentations (delivered in SL) on the mirror neuron and 'backformation' effects
SecondLife enables, both of which relate directly to their research on the Proteus Effect.
I also have the academics' names and contacts for you.
[10:19 AM] Carolyn Carillon: MN: This is our contact info on the screen now
[10:19 AM] LV (lorivonne.lustre): crowd@bcm.edu
[10:20 AM] LV (lorivonne.lustre): mnosek@bcm.edu
[10:20 AM] ThomasM Torok: Margaret - you might give the reference where some of this
work is published in the literature

[10:20 AM] Shyla the Super Gecko (krijon): Can I voice a comment
[10:20 AM] LV (lorivonne.lustre): Shyla: my avatar is small and friendly and open to listening
It also claims to be super!
Behind it is someone very strong
I find that sometimes people assume that small avies are not as strong. This is not so

I'm kinda the opposite
And I don't know why
In RL I'm really obnoxious (laughs)
In SL, I'm much more respectful and compassionate
and insecure
because I don't feel like I move around very well
I'm not expert at moving my avatar
I don't have the time to invest in learning
If I could just learn how to give a high five
that'd be cool
But I haven't figured that part out yet
I admired all of you who have beautiful outfits
My inventory is a mess
I can't figure out how to find anything
Acquiring clothes I like takes SO MUCH time
HOURS
Trying to find stuff
So I'm much more insecure here
So we're the opposite, Shyla
[10:23 AM] Shyla the Super Geck (krijon): VAI has folks who do inventory organization workshops once in a while, that might help...
[10:23 AM] Svea Morane: Perhaps we need Stephanie's perception of your first life self ;)

[10:24 AM] Carolyn Carillon: SS: I'm the same here & in RL
Although I would be a bit more concerned if I was suddenly naked in RL!

[10:24 AM] GraceyLaceyLou: "may i pweafe voice a commeng!"
[10:25 AM] Carolyn Carillon: GRACEY: one thing I love
In RL I can't drive
but in SL, I can drive
[10:25 AM] Gentle Heron: Good for you Gracey
[10:25 AM] Carolyn Carillon: MN: I would love to try that too
I can only drive my wheelchair
And not very well

[10:25 AM] Gentle Heron: QUESTION: Why do you consider using ramps in SL instead of steps to be a political statement? Couldn't it be a form of modeling best practices for RL?
[10:26 AM] Carolyn Carillon: MN: I like that
I think you're right
It could be
Universal design is a mindset
It's a throwback to the old days to even have steps
You're right
When they say all kinds of things
About the way things were
Those kinds of statements
of the way things were
are really saying
Let's make everything exclusive
Let's leave people out again
You're right
We have to eliminate that from our consciousness
We need to let everybody in
That's a really good statement, Gentle
How can we promote that?
Maybe like you have here
Virtual Ability is completely accessible
And there's nothing unusual about it
There's no reason why this couldn't be done in RL

[10:27 AM] Pecos Kidd: Look at the design of this auditorium, for example.

[10:27 AM] Gentle Heron: I'd like Em (EC) to speak to that please.
Em head the build team for this island!

[10:27 AM] LV (lorivonne.lustre): EC: I was on the build team

Part of the process was to model best practice, but to look completely normal
There are no signs that say this is done this way for accessibility. There are no steps anywhere out of respect for universal design
It was part of our mindset. That you can build with respect and to show how it can be done

I love it
All of SL should be like this
I admire you for doing that
One more question I'd ask
You all have people you've tried to bring into SL
How do you help them overcome that fear?
Of being in an environment that could be disorienting?

[10:30 AM] Gentle Heron: QUESTION: How hard is it to find academic colleagues to work with you inside a virtual world environment? How hard is it to convince people with little computer experience to try out a virtual world as a research subject?

[10:30 AM] Carolyn Carillon: MN: Really it's all or nothing
I find my colleagues have an open mind
Or are absolutely opposed
There's no middle ground
If they're not computer savvy it's a moot point
They don't have the tech available to do it anyhow
If they did have it they'd be open to it
I deal with lots of folks
The highest tech they have is a cricket phone that can't even access the internet
There's a whole level of society that can't access tech
So we have to help them tap into what's available
They're open but it's about access to resources
It's shocking among academics
Some people just have closed minds
They can't get out of the 20th century
They're not open
It's sad

[10:30 AM] Gentle Heron: How do we help people get over that initial fear? (question to the audience!)

[10:32 AM] iSkye Silverweb: Even if they are computer savvy, many make assumptions about 'oh, I know what to do' and it can be an eye opener but it can also be a very liberating experience
Once you get them IN here, they see the possibilities
LV (lorivonne.lustre): SS: as far as using SL -- we used to use it more in our department even with course work

Svea Morane: My experience is that the barriers, responses and mindsets for using virtual worlds with colleagues and the general public is about identical to when I was bringing the Web into our organization back in 1980.

LV (lorivonne.lustre): SS: it is not as much right now.

Carolyn Carillon: MN: the younger generations
It's a no brainer
They're into technology
So it's no problem for them
It's the middle and older generations
They're hard to convince
And then academics
have the excuse
"I'm too busy"
I don't have much patience for people with closed minds
It's a fear
I get concerned when we have participants who are trying hard to learn and then they'll go off and get stuck in a bush or in trees and they're screaming for help they're really afraid
They feel out of control
We do everything we can
Stephanie is a facilitator for those people
She does everything
She calls on the phone
She texts with them
to help them calm down
It's been pretty successful
They come back
and gain confidence
Have you had experiences of talking people down & allaying their fears?
We've even got one co-investigator who will not go off island because she doesn't want to be assaulted
What are you talking about?
Just click the home button!

Pecos Kidd: Teach them how to "teleport home" whenever they are stuck or lost.

Carolyn Carillon: MN: But she's so afraid of exploring
She has to be in control
That makes her a great researcher
But wow
She's afraid of the environment

Gentle Heron: It also means you created a safe environment for her, which is good.

Carolyn Carillon: MN: that's true
I guess that’s progress
We’ve dragged her kicking and screaming into the technology
So we have made some progress if she feels safe
[10:37 AM] iSkye Silverweb: it does take time, there is a learning curve but there is also the safety factor
[10:38 AM] Mook (mook.wheeler): there is always fear in the beginning with something new, but that will fall away as she gets in more practice and experience

[10:37 AM] Carolyn Carillon: MN: Thank you all for your comments
Feel free to contact us
Go to our site
Check out what we’ve done
We just got some new grant funding to expand our research
We’re doing the GoWoman project with both men & women with spinal cord injuries
So we’re plowing ahead
My goal is to make these interventions available here in Virtual Ability Island
I need your help in helping everyone appreciate this wonderful world
[10:38 AM] Gentle Heron: Thank you Dhira and SLSlivei. Your work is wonderful to know about. A good use of the virtual world.
[10:38 AM] LV (lorivonne.lustre): SS: thank you for having us and for all the feedback. It was great.

[10:38 AM] LV (lorivonne.lustre): <transcription ends>

[10:38 AM] Gentle Heron: During our break, please consider visiting the displays and exhibits on Healthinfo Island. Many relate to this presentation about l’Arche.

Displays:
The l’Arche Story http://maps.secondlife.com/secondlife/Healthinfo%20Island/196/157/23

The History of the Independent Living Movement
http://maps.secondlife.com/secondlife/Healthinfo%20Island/190/179/24

Why is Community Important to People with Disabilities?
http://maps.secondlife.com/secondlife/Healthinfo%20Island/172/154/22

Exhibits:
Jean Vanier on Disability
http://maps.secondlife.com/secondlife/Healthinfo%20Island/113/78/24

What Defines Community
http://maps.secondlife.com/secondlife/Healthinfo%20Island/96/41/26
The Role of Organizations for People with Disabilities
http://maps.secondlife.com/secondlife/Healthinfo%20Island/51/27/28

Jean Vanier on Community
http://maps.secondlife.com/secondlife/Healthinfo%20Island/25/25/30

What do you call people with disabilities?
http://maps.secondlife.com/secondlife/Healthinfo%20Island/21/63/32